

Dear Friend of Swifty,

In a previous Impact Report, Patti suggested pouring yourself a cup of coffee to enjoy while reading over Swifty's accomplishments. This year you may need a scotch. Exciting and wonderful changes are underway!

In the 11+ years since Michael announced his "Master Plan" and donated his own post-mortem tissue to help others, Swifty has developed the national program Gift from a Child (GFAC) so during their darkest time other families can make that same choice.

The most important questions Swifty now faces are: 1) how can GFAC's operations and financial sustainability develop beyond its relationship to the Swifty Foundation? 2) how can these precious gifts of tissue best lead to better treatments for childhood brain cancer? The answer to both questions is the Children's Brain Tumor Network (CBTN).

We know the research that happens **after** the tissue is donated is just as important as the tissue itself. CBTN is a research-based consortium of 34 children's hospitals around the globe. The GFAC program is now officially part of the CBTN and Michael's Master Plan has been supercharged!

We have outlined the details of this supercharged plan in the pages that follow. And although as you will see in these pages our Swifty team will remain fully involved in GFAC, the foundation will no longer fundraise. This will remove much administrative work, allowing us to focus our time on the further development of GFAC and Michael's Plan.

This doesn't mean we are not still counting on your financial support. We have created the Michael's Master Plan Fund at the Children's Hospital of Philadelphia's Foundation that will support GFAC going forward. Our Swifty team will have oversight of the fund through 2030.

We still need you as much as we ever have and together we will accomplish Michael's Master Plan!

It's time to pour that scotch and settle in. This is our most important impact report to date. We invite you to read every word, but most importantly pg. 6, Michael's Master Plan Fund.

Until there is a cure,

Patti Gustafson
Director

Al Gustafson
Board Chair



MICHAEL'S MASTER PLAN AND THE BIRTH OF GIFT FROM A CHILD:



We want to share some of our origin stories you may not have heard. These are some of the key events that have shaped the evolution of Michael's Master Plan.

It Began with Michael & Martine

Of course, Michael is the man with the plan, but his plan to "use himself to find a cure" could never have happened without his pediatrician, Dr. Martine Nelson. She came to the hospital for Mikey's CT scan that revealed the cause of his headaches and vomiting, and before we gave the news to Michael, she prayed with us. When Mikey asked her if he was going to die, she answered, "That's not our plan." Do you see the grace in that? It calmed his fears while promising nothing. She knew it wasn't in her hands, but she was going to do everything in her power to heal our boy.



And heal she did. In all the most beautiful ways. She was honest with him, she spoke to HIM, not to us. She involved him in decisions giving him a sense of agency when life felt so out of control. They made each other laugh, they played together with his puppy. Yes, she made house calls. Many house calls, dropping off prescriptions and then sitting on his bed talking about Harry Potter, the Red Sox, normal stuff.

And it was Martine who did all the work GFAC tissue navigators now do for families; she handled the logistics so Michael's final wish to donate his tissue could come true.

A Chance Encounter? NOT A CHANCE!

In 2016, Patti and Al traveled to NOLA for their very first scientific research conference and it was there the seeds of Michael's Master Plan were planted. Sheepishly they approached presenters from the Children's Hospital of Philadelphia (CHOP) and told them Michael's story and Swifty's interest in helping other families to donate tissue. The result was a trip to Philadelphia where they met Dr. Angela Waanders and were introduced to the Children's Brain Tumor Network. Working with Angela and the CBTN team that summer led to starting a formal post-mortem collection program at CHOP. We knew then without a doubt, Michael was on to something!



Swifty 2016 Annual Appeal



The Birth of the Tissue Navigator

It was over a lunch of Potbelly sandwiches in the atrium of Lurie Children's Hospital with Dr. Rishi Lulla, who we also met at the conference in NOLA, that a job description outline for what would become a GFAC tissue navigator was created. It took a while for it all to be approved, but when the Swifty Junior Board presented the check to Rishi and his team, Swifty had a model for other institutions to replicate and a path for scaling up the work of post-mortem (PM) tissue collection across the country.

LOOK BACK

To the Rescue...

Social media, website development, attending more conferences were all critical to building relationships to support Michael's Plan. Swifty used a PR firm for help until we considered hiring a full-time employee. Our PR contact, Ginny McLean, was as excited about our mission as we were. So, we took a chance and offered her a job. Ginny took a bigger chance, working for a nascent foundation run by bereaved parents and a junior board of high school and college students. And she fit right in!

If Swifty were a jigsaw puzzle, Ginny was the missing piece. She's a whiz on all things techie: social media, graphics, organizing a CRM to streamline Patti's communications a hundred-fold and website building. Best of all she's a networking maestro! She's made incredible connections for us and she loves doing it. She handles tissue donations with so much compassion and care for our GFAC families. She's got a huge heart and everyone loves her. Especially Patti and Al!

IMAGES TO RIGHT: Ginny at AAHPM and with Drs. Michelle Monje & Mariella Filbin



A Pathway to Understanding

In 2017, Al was invited to participate on both the Advisory Council and Executive Committee of the Children's Brain Tumor Network. Having only made it to high school biology, he was in way over his head, but learned much from the researchers, doctors and heads of other charities. The challenges for advancing pediatric brain cancer research became clear. What happens with the tissue **after** it is donated is just as important as the tissue itself. Because CBTN's model of open science and collaboration gives children's donated tissue the best chance of accelerating breakthroughs, Swifty has invested more than \$2.5m to strengthen CBTN's infrastructure.



The Club Nobody Wants to Belong to

In 2018, we gathered families from across the country who had lost a child to brain cancer, some having donated tissue, others had not. Our goals were to learn about their child's journey, to work on messaging, to build relationships in this community and find good advocates for PM donation.



The two days of conversation led to much of the language we use today when educating medical teams about approaching families for donation as well as for our marketing materials and Gift from a Child's website. Prior to the forum each family filled out a survey about PM donation. This survey led to our larger survey and our subsequent publication in the *Journal of Clinical Oncology* on the family's perspective of post-mortem (PM) donation.



MICHAEL'S MASTER PLAN AND THE FUTURE OF GIFT FROM A CHILD:



If Michael's Master Plan was once a busy four-lane highway, it is now an eight-lane expressway. Traveling in the same direction with much more capacity and speed to get us where we all want to go ... to better treatments for children with brain cancer.

Gift from a Child Moves from the Bedroom to the Boardroom

Since 2016, the GFAC operations center has been a standing desk at a bedroom window, a front hall closet and a mailbox in Woodridge, IL. This summer the operations center has moved to the offices of the Children's Brain Tumor

Network (CBTN) in Philadelphia, kind of like the Jefferson's "movin' on up to the east side" in the '70's sitcom. We are overjoyed for what this means for the GFAC program and thrilled to tell you all about it!



GFAC + CBTN = COMPLETE

Most simply, GFAC focuses on everything leading up to and through a PM donation. CBTN is a research-based consortium made up of 34 children's hospitals around the globe. CBTN focuses on everything required to maximize that donated tissue's potential to accelerate breakthroughs in childhood brain cancer. For families, this means confidence their child's tissue will make a difference. For the worldwide research community, this means free and open access to more PM tissue and the data it generates. To borrow a line from Jerry Maguire, GFAC & CBTN "complete each other."

Due to the merger, the future of GFAC will be shaped by some of the best scientific minds working in pediatric brain tumor research and the MBA's and project managers who understand the science and know how to get things done.



LOOK Ahead

GFAC Operations: A New Look

It has taken two years of monthly leadership meetings, the work of five committees, and lots of can-do attitude from the Swifty and CBTN teams to work out the details, create a vision and strategic plan for merging GFAC into CBTN. Our plan is built around four areas of focus 1) Post-mortem (PM) Donations 2) Outreach & Education 3) Translational Research 4) Program Mgmt & Financial Sustainability. Happy to share the details with any Swifty donor (email patti@swiftyfoundation.org) but here are some highlights:

What Remains the Same:

- The mission of GFAC is to make it possible for any child to donate PM tissue and to change the culture so all families are given the opportunity to donate PM tissue.
- The 7 Regional Centers of Excellence, a tissue navigator at each location, working together to serve all families and medical teams across the country.

What's been Upgraded (Oh, So Much!):

- The CBTN has changed its research protocol to add the collection of post-mortem (PM) tissue through GFAC. There is now a formal expectation that all CBTN member institutions will make PM donation available to their families.
- A new position, GFAC-CBTN Manager of PM Operations, was created to be the liaison to all the CBTN member sites, training staff and helping coordinate donations. The position reports to the Director of Clinical Research Ops at CBTN.
- Swifty's Ginny McLean will fill the new position of GFAC Program Director and be responsible for the strategic direction, leadership, and oversight of the GFAC program at CBTN and report directly to CBTN's Executive Director.
- A GFAC Post-mortem (PM) Working Group was established to accelerate research breakthroughs using PM tissue by enhancing scientific collaboration between the Centers of Excellence. We have some of the best researchers in the country on this first project. They will longitudinally map the evolution of a patient's tumor from diagnosis to death, capturing the genomic and clinical data from all stages of a patient's disease history. These maps will be created for every disease type and available for any researcher to interrogate.
- The Swifty team, Patti, Deb and Al will continue to provide direction & leadership meeting twice a month with the CBTN team: one for OKR progress reporting and one for strategy.



GFAC-CBTN STRATEGIC PLAN

- 01 Operational Process
- 02 FY 25 Focus Areas
- 03 PM Donations
- 04 Translational Research
- 05 Outreach & Education
- 06 Program Management
- 07 Financial Sustainability
- 08 Milestones & Reporting



Children's Brain
Tumor Network

What Happens to SWIFTY?



The involvement of Patti (director), Deborah du Vair (Swifty's MBA/project manager) and Al (board chair) will remain mostly the same, except Swifty will no longer fundraise. This will eliminate much of the admin work of running a public charity and is a big step in our succession plan. If Michael's Master Plan is to make the impact we all know it is capable of, it must live beyond its founders, allowing new leadership to develop his plan in ways we couldn't even dream of.



Swifty team: Deborah, Patti, Nikki, Ginny & Al



Michael's Master Plan Fund

Here is another Jerry Maguire reference, "Show me the money!" Not to be crass, but when there is no money, there is no mission. In the coming years, as GFAC expands through CBTN's research-based consortium, there will be opportunity to diversify the funding streams supporting the mission... grants from the National Cancer Institute, Big Pharma, the Department of Defense (yes you read that right) to name a few.



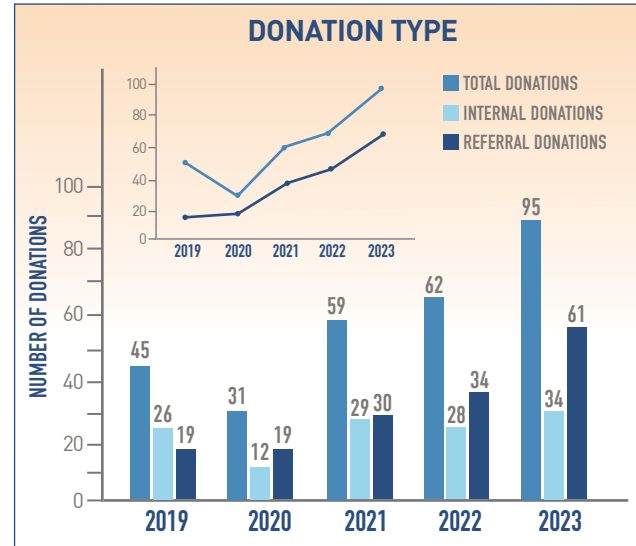
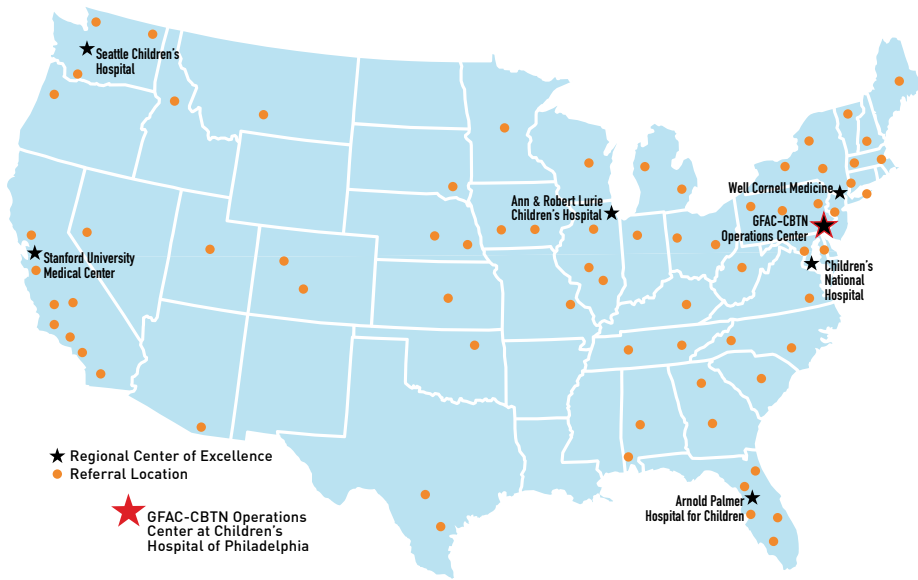
Swifty wants to provide a long enough "funding runway" to allow time for these new funding sources to takeoff. **We estimate it will take 5-7 years before GFAC secures enough alternate funding streams to make it sustainable without Swifty's help.** To provide the runway that will continue to fund GFAC we created the Michael's Master Plan Fund (MMPF) at the Children's Hospital of Philadelphia Foundation.

Swifty made a \$744,886 gift in the spring of 2024 to establish the MMPF and fund the GFAC operations center at CBTN through 2027. **The fund will financially support GFAC in all the ways the Swifty Foundation has these past 8 years.** It will fund salaries for tissue navigators, autopsy costs, advocacy and education work, and GFAC based research. **Our Swifty team will have oversight of the MMPF.** In addition, our family made a commitment to contribute \$3M over the next six years to the MMPF.

This fall our Annual Appeal will invite our Swifty supporters to make their gift to the Michael's Master Plan Fund and support Gift from a Child. Greater detail on the future funding and program costs of GFAC can be found on page 9.

GFAC Metrics

The success of GFAC advocacy is clear. This map shows the hospitals that have referred patients to GFAC (often multiple times each). This demonstrates our goal of changing the culture around pediatric PM donation is happening!



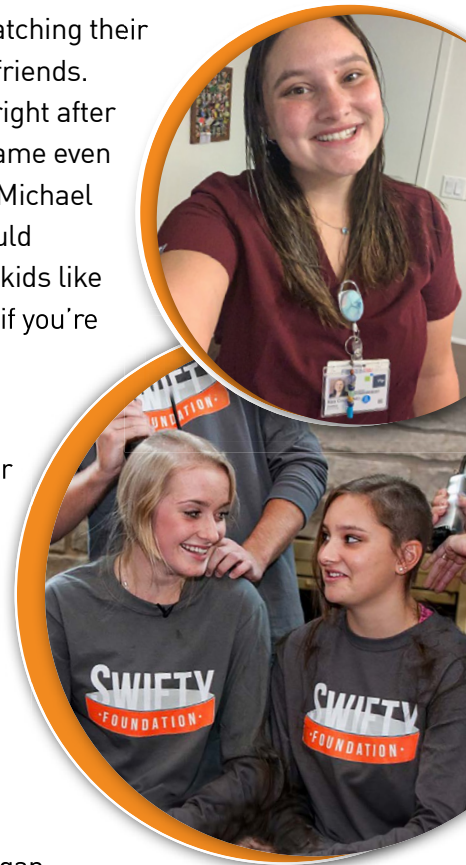
SOUL FOOD

by Kira Couch

Michael, Bridget and Kira met as toddlers watching their big brothers play baseball and became best friends. Kira's mom went through cancer treatment right after Michael and cancer's impact on a family became even more personal for her. As she companioned Michael to the very end, she told him one day she would become a pediatric neuro-oncologist to help kids like him. Pipedreams of a young teenager?... not if you're Kira Couch.

Kira became a leader on our Swifty Junior Board, shaving her head twice and raising over \$40K in the process. In college, she spent a summer in DC lobbying for the Creating Hope Act which incentivizes companies to create childhood cancer drugs and she chaired IUPUI's Danceathon supporting Riley's Children's Hospital in Indy. In medical school, Kira stayed connected to Swifty and GFAC as a member of our governing board .

And in the summer of 2024, Dr. Kira Couch began her residency training in pediatric neuro-oncology at the University of California San Francisco. Sometimes dreams come true so even bigger dreams can come true. Kira became a doctor, and she is going to help lots of children who are just like her pal, Mikey.



IMAGES ABOVE:
First Image: Dr. Kira Couch UCSF Children's Hospital
Second Image: Bridget & Kira shaving their heads senior year of high school

GFAC By The Numbers

The potential of Michael’s Master Plan and the program of the Gift from a Child program has exponentially increased because of its merger with CBTN. We hope the previous pages of our Impact Report have demonstrated why this is true. However, the mission will prosper only if there is funding to fuel it. Here is a look at some of the details and assumptions we made for the next six years of funding GFAC and ensuring its sustainability beyond the Swifty Foundation.

DOLLARS IN THOUSANDS		Starting Balance	FY24-25	FY25-26	FY26-27	FY27-28	FY28-29	FY29-30
REVENUES								
	Swifty Donors		150	150	100	100	75	75
	New GFAC/CBTN Fundraising		50	100	200	350	500	600
	Gustafson Family		750	750	500	500	250	250
	Interest Income		25	25	25	25	25	25
	TOTAL REVENUE		975	1,025	825	975	850	950
GFAC PROGRAM COSTS								
	CBTN Operations		257	255	264	273	283	294
	Centers of Excellence		444	427	388	354	323	296
	Advocacy		75	75	75	75	75	75
	Research		200	200	200	200	200	200
	TOTAL EXPENSES		976	957	927	902	881	865
	NET INCOME (LOSS)		[1]	68	102	73	[31]	85
MICHAEL MASTER PLAN FUND BALANCE			745	744	812	710	783	837

Establish Michael’s Master Plan Fund

In 2024, Swifty granted \$744,886 to establish the Michael’s Master Plan Fund (MMPF) at the Children’s Hospital of Philadelphia Foundation. The charter of MMPF is to fund all the operating costs of the Gift from a Child program just as the Swifty Foundation has done these past 8 years.

Counting on Our Swifty Donors

We are counting on past Swifty donors to continue supporting Michael’s Master Plan through MMPF. We absolutely will need your help to be successful. In our budget planning, \$650K will come from Swifty donors. Although your gifts will now go to MMPF at the CHOP Foundation, every dollar of your donation will support Gift from a Child.

Our Swifty team will have oversight of the fund through 2030 helping direct grants and evaluate their impact.

And part of the responsibilities of the GFAC Program Director at CBTN (you know, Ginny) will be securing new revenue streams.

Gustafson Family Gift

The Swifty Foundation was started using the money we saved for Michael’s college and wedding (kind of like his own little dowry). Our family’s donor advised fund at the DuPage Foundation will make a gift of \$3M to support the MMPF over the next six years to celebrate Mikey and reinforce his Master Plan.

GFAC Operations @ CBTN

This includes the newly created positions of GFAC Program Director and GFAC-CBTN Manager of PM Operations.

GFAC Centers of Excellence

Funding will continue to support tissue navigator salaries and autopsy costs at each of the GFAC centers of excellence. Each institution has agreed to find additional funding to support GFAC work at their site. The plan is to enter into two-year gift agreements with centers beginning in 2025 reducing the funding they receive from MMPF by 20% with each new agreement.

GFAC Research

We are planning \$200K/year (a projection we will adjust depending on revenue) to fund research using GFAC tissue. This project is directed by the newly established GFAC PM Working Group, led by researchers from GFAC, CBTN and Deb and Al from Swifty. The working group’s first project will be mapping the evolution of a patient’s tumor, capturing both clinical and genomic data, from diagnosis to death. Creating an incredible resource for understanding how the biology of the tumor evolves and evades treatment.



Gifts that touch us so:

Memorial Gifts

Thank you to all the GFAC families who donated their child's memorial gifts to GFAC.

Thank you to all our family/friends who have donated their loved one's memorial gifts to Swifty.

Monthly Gifts

Al & Marci Mitchell, our very first monthly donors, have been generously supporting Swifty with a monthly gift since 2014! Our monthly donors not only help us with long-term planning, they also strengthen our sense of community that we are doing this together!

Everyone Needs an Uncle Bob

Michael's Uncle Bob gives generously each year, but our favorite gift comes with a heartfelt message and hand delivered card on Bridget and Mikey's birthday.

You Know Who You Are

Those who give that really don't have extra to give, but do so anyway.

Community events to raise money for our program

Smash Cancer in South Bend, Lemonade and Golf in Naperville, Tennis in Hinsdale. We appreciate every effort big and small to raise awareness and funds.

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- ◆ Donors who have Given Every Year Since 2015

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